CHILDREN'S Heart Network | Heart Matters

WWW.CHILDRENSHEARTNETWORK.ORG SUMMER 2016


Brandon with his mom Norma and his dad Martin – ready for the big game!

Brandon's wish come true: Meeting the Mexican national soccer team

BY NORMA CRUZ

My son Brandon loves soccer and his favorite team is Mexico. On March 25th, he was given the chance to meet and watch the Mexican national soccer team. This opportunity was made possible because of the generosity of people who give to Kids Up Front. This was an amazing experience and one he got to share with his closest family members. He wore his Mexico team jacket, which he has had for years. He yelled, cheered, smiled, laughed, and had the time of his life.

"It looked like he was just overwhelmed with so much happiness he didn't know how to get rid of it," his sister said. "He was laughing and cheering and jumping up and down whenever Mexico scored! It was so beautiful to watch." She was emotional about being able to share this special moment with her brother. "I never actually saw myself being able to do these things with him, as we thought he would leave us soon. But much like any other younger brother, this cute little guy is here for a long time."

Brandon's story is much like any other heart story; hectic and emotional, but endearing. On April 19, 2006, I went to the hospital to deliver Brandon. We knew he was a heart baby so it was terrifying. I was shocked by the number of doctors in the room. Brandon was diagnosed with hypoplastic left heart syndrome. When Brandon was 4 days old, he underwent his first open heart surgery, the Norwood procedure. That is when I saw what a strong and brave baby he was. When he was 8 months old he had

—continued on page 3

The newsletter of the Children's Heart Network, which works to educate, support, and enhance the lives of children, youth, and families living with congenital heart disease.

IN THIS ISSUE

Volunteers needed

Our families enjoy the spring, summer, fall, and winter gatherings that CHN sponsors. We are always looking for volunteers, so if you have some time, talent, and expertise that you are willing to share, please contact Sam Aitken at: **saitken@childrensheartnetwork.org.**

Heart Matters
5151 Canada Way, Burnaby, BC V5E 3N1
Tel: 604 521-3037 | 1 877 833-1773
chn@childrensheartnetwork.org
ChildrensHeartNetwork

COFFEE GROUPS—THERE'S PROBABLY ONE IN YOUR NEIGHBOURHOOD

These groups meet monthly; come and meet other heart parents while enjoying treats on CHN. For more information please contact:

ABBOTSFORD – Rachel Gammon
footballmama02@hotmail.com

BURNABY/COQUITLAM – Sarah Kertcher
sarah.kertcher@outlook.com

CHILLIWACK – Melissa Martz
mellymartz@outlook.com

KAMLOOPS – Miranda Brown
cmazn2003@yahoo.ca

KELOWNA – Karla Allan
kdvk@hotmail.com

LANGLEY – Tecia Beulens
tbeulens@telus.net

MAPLE RIDGE/TRI-CITIES – Amylou Watkins
amylouwatkins@hotmail.com

NANAIMO – Andrea Van Rossum
andrea.vanrossum@gmail.com

PRINCE GEORGE – Veronica Vandermeulen
veronica0603@gmail.com

RICHMOND – Kate Walker
kwalker@childrensheartnetwork.org

VANCOUVER – Samantha Aitken
saitken@childrensheartnetwork.org

VICTORIA – Teri Godin
terigodin@gmail.com

YOUNG ADULT HEART NETWORK COFFEE GROUP

We have a group for young adults living with heart disease. For more information please contact:

Lauren Fougner | lfougner@uvic.ca

ARE YOU A MEMBER OF A HEART FAMILY?

If you have a child growing up with heart disease please email us at **chn@childrensheartnetwork.org** so that we can add you to our mailing list to receive invitations to all our fun events!

THANK YOU TO OUR GENEROUS DONORS

CHN would like to thank the following organizations for their support and generous gifts over the past six months:

The Province of BC

The CKNW Orphans Fund

HELPFUL WEBSITES

heartbeats.ca
Supporting Children with Heart Disease

chdquilt.org
The Congenital Heart Defect Awarenees Project

westerncanadianheartnetwork.ca
Western Canadian Children's Heart Network

achaheart.org
Adult Congenital Heart Association

cchaforlife.org
Canadian Congenital Heart Alliance

CHN STAFF

SAMANTHA AITKEN – Provincial coordinator

PATTY RIPPEL – Administrative assistant

KRISTI COLDWELL – Lower Mainland Hearts of Gold youth coordinator

MEGAN MADSEN – Vancouver Island Hearts of Gold youth coordinator

CHN BOARD

TRACEY CARPENTER – President

MANDY JOHNSON – Past president

JEFF MERCER – Treasurer

BARB WILLSON – Secretary

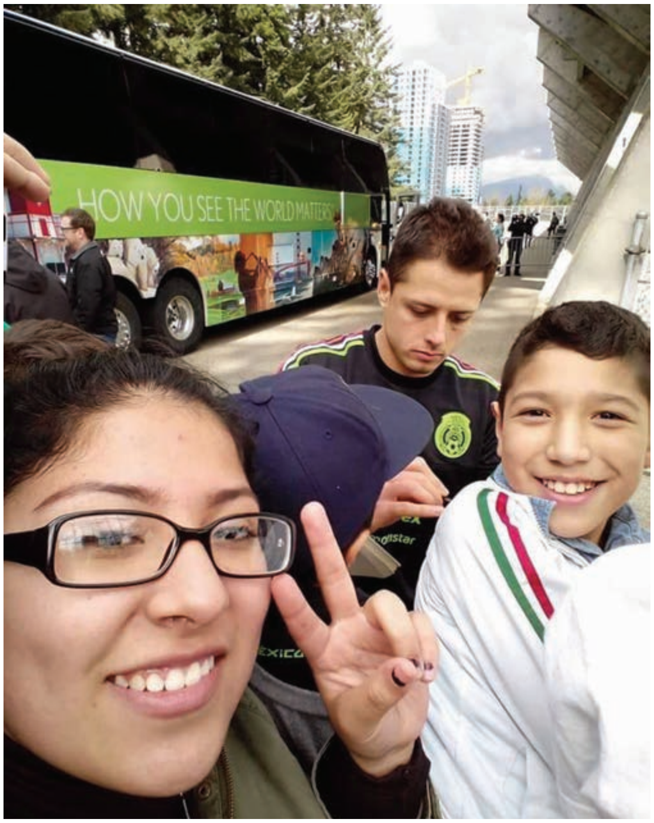
BARBARA JOHNSTON – Member at large

KERRY HARDING – Member at large

STEPHANIE ISAAC – Member at large

CAROLINE CASSIDY – Member at large

LINDA ADAMS – Member at large



his second open heart surgery, the Fontan procedure. At 3 years old he had his final surgery, the Glenn procedure. Brandon has had oxygen tanks, needles, IV lines, drainage tubes, and many more invasive procedures. One would think that would cause a baby to be happiness-deprived, but not Brandon. He has always proved people wrong; he is constantly positive and happy.

Brandon is complimented everywhere he goes, from "he is such a good-looking boy" to "what a pure heart!" He always shares, and makes sure to help others. His words are "Mommy, why stand back and watch them suffer, when I'm right here and I can help?" I am so proud of my little blessing and so thankful that he received those soccer tickets. He has another good memory to add to his life, and hopefully a story he can tell his children.

We are so grateful for all the support that the Children's Heart Network has provided and we would like to give enormous thanks to the people who donated the tickets and to Kids Up Front. Brandon and our family will never forget that day!

Brandon and his big sister Hillaria.

Wine Gala dinner sets new fundraising record

BY SAMANTHA AITKEN

Some of the awesome Gala volunteers.

On Friday, April 29th the Children's Heart Network held its 14th Annual Wine Gala Dinner at the Diamond Ballroom in Vancouver. Over 180 guests enjoyed gorgeous city views, a fabulous dinner with wine pairings, and both live and silent auctions. It was CHN's premiere fundraising event of the year.

The evening started with a glass of See Ya Later bubbly and canapés while guests admired the view and perused the silent auction items. This room was buzzing! Guests sat down to enjoy dinner prepared by executive chef Matthew Kamieniecki while our emcee for the evening, local actor and heart dad John Emmett Tracy, entertained us with both his wit and heartfelt reflections.

We were enlightened as heart parents Kristin and Mike Avis from Nanaimo shared stories of their heart journey with their son Judah. They spoke of how the Children's Heart Network has supported them along the way. They attended the Growing Up with Heart Disease conference in 2015 and have since helped to grow the Nanaimo CHN chapter to a thriving group of families.

Lisa Lalsingh then shared with us how she and her husband Dustin Dickout have formed Mila's Fund, a special fund within the CHN. This fund is in memory of their beloved daughter Mila, who they lost to Congenital Heart Disease. Mila always wanted to go to camp so this fund is to help support getting our heart kids to camp every summer. You can designate your CHN donation to be directed to Mila's Fund.

Sending more heart kids to camp is one of CHN's goals this year, and thanks to the energy of our auctioneer Robb Lucy and the generosity of our guests, we collected donations totaling more than $15,000 to benefit our kids heading to Camp Zajac this summer. The evening culminated with the Glasses On/ Glasses Off game and the winner took home a trip for two to the Burrowing Owl Winery. In total, we raised $55,000, which makes it our most successful year ever. Children's Heart Network families will benefit greatly thanks to the generous support of all our attendees, supportive corporate sponsors, and auction donators. Thank you to all of our guests, donators, and the following major sponsors:

- Dean Alexander
- The Pediatric Cardiology Associates
- Dr Brian Sinclair
- Riverrock Casino Resort
- Rosanna & Edgar Rahal
- RBC Wealth Management
- Air Canada
- Burrowing Owl Winery
- Colby Red wine
- Chateau Ste. Michelle Winery
- See Ya Later Ranch Winery
- Cindy Thaler

Next year's gala is already booked: mark your calendar for Friday, May 5th, 2017!

A jam-packed weekend of fun at Zajac Ranch

BY MEGAN CRANE

Teepee fire pit fun!

The consensus is that this was the best camp ever, and I have been a counsellor since 2008! It started like any other camp; catching up with old friends and making new ones on the bus to Zajac Ranch, located in Mission. Once at Zajac there was the mad rush to get meds dropped off at the OK Coral so that one could pick a prime bunk in the dorms. Catching up with those friends who weren't on the bus, learning (or re-learning) the Zajac rules, meeting the counselors. The day ended with a counselor hunt (they had some really good hiding spots), campfire, and s'mores.

Day 2 was jam-packed. Everyone was split up into two groups and headed off to the various activities. A lot of people challenged themselves with the high ropes course—even a few who are afraid of heights stepped out of their comfort zone. Archery saw some bull's-eyes, and canoe/kayak ended in a rousing game of shark vs. minnows, and for one group a not-so-dry attempt at piano

—continued on page 6

keys. There was the photo scavenger hunt and riff-off, which were lots of fun. The day was capped off by the annual Hearts of Gold talent show. This year we had a make-up demonstration on two willing male participants, a blinding fast Rubik's cube demonstration, vocal impersonations, a guitar solo, rap jam, and Adele's song "Hello" being "crushed to the ground" by our singing superstar.

Day 3 saw some more climbing action in the form of the climbing wall and a chance to do some horseback riding. Zayo was unfortunately cancelled do to the weather, but a controversial game of capture the flag took its place. Trivia dump saw all campers answering trivia questions correctly, resulting in four poor counselors getting everything from cold water and flour to ketchup, mustard, and oil dumped on their heads. The day was rounded out by a pool party and movie night with tons of snacks for everyone.

It was an amazing weekend. Free time was filled with numerous card games, hanging out with new and old friends, and trying to find the elusive cell signal to send some texts. New campers were welcomed as if they were old friends, and all campers got to share their stories and try something new.

I can't wait till 2017.

Meet the new Board member: Linda Adams

Linda Adams joined the cardiology team in the Children's Heart Centre at BC Children's Hospital last spring as a nurse clinician. She began her career as a nurse on 3G—Cardiac Sciences at BCCH as a new grad and could be seen sporting her home-made dinosaur or Winnie the Pooh scrub dresses. She also worked on a couple of other units before joining the team in the PICU where she spent the bulk of her career before returning to her passion of working with cardiac kids and their families.

Linda was born in North Vancouver, grew up in the Lower Mainland, and now lives on the North Shore with her Vancouverite-husband, Andrew. They love the easy access to the mountain trails, ski hills, and ocean, as well as to ferry that frequently takes them to their off-grid cabin on the Sunshine Coast.

Linda is excited about the opportunity to serve on the CHN Board, to support and advocate for families of children with CHD, and to be a link between the CHN and the Heart Centre.

Did you know? First aid attendants at all VSB schools

In the Vancouver School Board, there are always first aid attendants with CPR training on site at schools. Typically, they are office staff. If you wish your teacher or child's aide to be trained in CPR, there is a department at the Vancouver School Board called "learning services" where the principal of your school can apply to in order to get funding for the training. If you are interested, please talk to your principal.

CHN now accepts donations of shares (and thanks to Mark Corra)

The Pacific Children's Heart Network (the full name of CHN) is pleased to announce that it accepts donations of shares of publically traded companies. Donating shares provides a significant tax deduction and capital gains exemption for the donor, while at the same time benefiting a worthy cause. Talk to your financial advisor for more information, and to see if donating shares is an option for you.

We would like to thank Mark Corra for his recent share donation to CHN of 5,000 B2Gold shares.

WHAT'S HAPPENING?

UPCOMING EVENTS

July 1 to 4
Heart Beats Summer camp at Zajac Ranch, for 7 to 12 year olds

August 28
Water Slides Picnic at Cultus Lake, for all ages

September 23 to 25
CHN's First Family Camp in Squamish at Camp Summit

For more information on all events, please contact saitken@childrensheartnetwork.org.

CHN NEWS

Goodbye to Dr Elizabeth Sherwin

It is with heavy hearts that we send good wishes with Dr Sherwin (lovingly known as Libby) as she leaves to take on a new position at Children's National Medical Center in her home town of Washington, DC. Dr Sherwin will continue to work as a pediatric cardiologist and electrophysiologist, predominantly focusing on arrhythmias, pacemakers/devices, and inherited heart rhythm diagnoses. Dr Sherwin has been a tremendous addition to the CHN Board; we will miss her wisdom, passionate commitment to supporting heart families, and her wonderful smile. Thank you so very much for all that you have done for our BC heart families. Best wishes Libby!

Welcome to baby Kainui

Krista Molia (Victoria Hearts of Gold coordinator) and her husband Sipili are thrilled to announce the arrival of their fourth child, Kainui Saunoa José Molia. While Krista is away on maternity leave, Megan Madsen is our Hearts of Gold coordinator in Victoria. Congratulations to the Molia family!

NOTABLE DONATIONS

Hunter's 3rd Annual Pancake Breakfast

We had a wonderful turnout for Hunter's 3rd Annual Heart Pancake Breakfast to raise funds for the Children's Heart Network. People came from all over: the Tsawwassen First Nation and Delta community, some of Hunter's teachers and EAs from Ladner Elementary, and of course our family and friends. Everyone stayed and had a great visit.

Hunter's heart journey began when he was born with tetralogy of Fallot, a congenital heart defect. At 2 days old he had a shunt surgery to help increase the blood flow to his lungs. When he was strong enough, at 8 months old, he had open-heart surgery. As Hunter grows he will require more surgery. I am forever thankful to all the nurses and doctors at BC Children's, including, Dr Human, his cardiologist, and, Dr Campbell, who performed his open-heart surgery.


Hunter and his mom Andrea and younger sister Maddie and friend

The breakfast couldn't have happened without to our wonderful volunteers Bertha Williams (homemade pancakes), Dawn Williams (cupcakes), Gordon Blackett (photography), and Auntie Nikki Jacobs and Tyler Schadow (decorating and organizing).

The breakfast was held at Tsawwassen First Nation Recreation Center on Sunday, January 31st.

Fraser Valley Telus Community Ambassadors Club

Thank you to the Fraser Valley Telus Community Ambassadors Club for their support of CHN. Club president Linda Jackson and member Geoff Drewery presented CHN with a cheque for $1000 to fund CPR training for heart youth and families from the Lower Mainland and donated 25 pairs of hand-made mitts for heart babies. The Fraser Valley Telus Ambassadors are a group of dedicated volunteers who devote their time and energy to give back to their communities. In addition, Linda and Geoff also presented CHN with a cheque for $2000 to fund summer camp for heart kids and youth from the Telus Community Connections volunteer society. Our camp program has been an integral part of the services provided by CHN since 1992. Our Hearts of Gold camp focuses on youth aged 13-19 years and our Heart Beats camp is designed for children aged 7-12 years. We rely on the generous support of donors to carry out our camp program so thanks again to Linda, Geoff, and all your fellow volunteers for the work you do.

Geoff Drewery and Linda Jackson present CHN Coordinator Sam Aitken (centre) with a big cheque.

It doesn’t hold me back in any way

Sophia Draper sees her heart condition as just one aspect of her life so far.

This June, Sophia Draper is graduating from high school then heading to university. Later this year, she is also “graduating” from Children’s Hospital and transitioning to St. Paul’s Hospital. She was recently asked to define how she’s overcome adversity in her life so far. This is her response.

I was born with congenital heart disease and have been through many surgeries, procedures, and health challenges in my life. While these challenges have made school and some aspects of everyday life more difficult than most kids, I don’t see any of it as adversity necessarily. The challenges are all just different parts of my life, things I’ve had to cope with and overcome with the help of others.

My health challenges started before I was born when I was diagnosed with an AVSD and my parents were told I would need surgery at 18 months or two years. When I was born, my parents got an extra surprise: I needed coarctation repair when I was just two days old. The surgery went well, but I spent a lot of time in the hospital as a tiny baby. I was back at Children’s when I was three months old because I wasn’t gaining weight. While I was there, I caught a bad chest infection called RSV and had to spend 3 ½ weeks in the hospital. I went home on oxygen and was tube fed while my parents waited for a date for open heart surgery.

When I was six months old, I had an open-heart surgery to repair an ASD and my mitral valve. After that, I visited my cardiologist twice a year. As a kid, I didn’t realize that going for echocardiograms, ECGs, X-rays, and checkups with a cardiologist (first Dr Patterson when I was a baby and then Dr Sandor) wasn’t normal, so when I was seven years old and my parents told me that I needed another open-heart surgery, I wasn’t as frightened as a lot of kids would be. This operation was to replace my mitral valve with a mechanical one.

The surgery was a success. My surgeon Dr Leblanc gave me a new mechanical mitral valve and I was out of the hospital within a week. I had a lot more energy, but having a mechanical valve means I have to take blood thinner to prevent clots from forming on my valve. I have frequent blood tests to monitor how well the medication is working. If my blood is too “thick,” I’m at risk of developing a blood clot; if it’s too “thin,” I’m at risk of bleeding heavily. Fortunately, I’m not afraid of needles and we now have a home kit to make blood tests easier. I continue to see my cardiologist (who has been Dr Harris for the past several years) and have heart tests every year. I also regularly see a hematologist, pediatrician, and GP.

Unfortunately, I’ve had other health challenges. When I was 12, I began to get a lot of migraine headaches. The migraines started with a visual aura, where parts of my vision are blocked, after which the pain and nausea came on. In Grade 6, I started to miss a lot of school and found it hard to keep up in my classes. Because I have a heart condition, I couldn’t take most migraine medications and my parents searched for many ways to help me. I tried many treatments but nothing really worked until we found a Dr Leora Kuttner, a child psychologist who specializes in pain management. She taught me mindful breathing techniques and self hypnosis, which both help to relax my mind and ease the pain. I learned how to prevent migraines by thinking about things that relaxed me.

Right: Sophia, age 7, at Children's Hospital about a week after her surgery for a mechanical mitral valve. Below: Sophia and family in Monaco in 2014.

Grade 9 went really well for me—my grades went up, and I became friends with two girls with whom I started a community garden at our high school. I was expecting to have a similar grade 10 year, but my appendix burst at the beginning of the school year. I'm told that I have a high pain tolerance and this is why I didn't think very much of the pain, but a burst appendix is life threatening. I was lucky my stomach walled off the infection from the rest of the body so that the bacteria couldn't enter my bloodstream. I spent 10 days in the hospital, watched by a team of doctors while the infection was drained and I was given antibiotics. It took me months to recover because I developed severe anemia from loosing blood while in the hospital and I had very low energy for months. I was so tired all the time, I had to drop my extracurricular activities and focus entirely on school. I worried about being able to catch up and the impact this would have on my provincial exams. Luckily, my teachers enabled me to catch up at my own pace and I slowly got back on track and did well in my classes that year.

Taking blood thinners prevents me from playing any contact sports because the risk of an injury is too high. Having a heart condition has meant that running is much more difficult, so gym class has always been a challenge. To stay fit, I've taken dance since I was 7, which I love. This year I also started running—something that's been challenging, but I enjoy it and I completed the Sun Run in April.

For the past two years I've been in great health, continuing to make sure my heart is healthy, managing my migraines, and seeing my doctors. I've never felt particularly self-conscious about my scars—they are just part of who I am. I still see a lot more doctors than most teenagers, and I'll have to take Coumadin and monitor my blood for the rest of my life, but none of this brings me down.

Going to see so many doctors and specialists throughout my life has had a big influence on what I want to do after high school—I want to help children who have health challenges. I have had so many people help me: my family, my doctors, my teachers, and many nurses and other healthcare people, and I want to be able to help others in my career.

Next year, I am going to study psychology, linguistics, and anatomy at Simon Fraser University and Douglas College. I want to complete a bachelor's degree in developmental psychology with the goal of doing a master's degree in either speech language pathology or occupational therapy. Whichever career path I choose, I look forward to using my education and life experience to work with children to help them overcome their own health challenges.

I am very grateful to many doctors, nurses, and other heathcare people who have helped me throughout my life. I would not be here without them! A special thanks to my cardiologists Dr. Patterson, Dr. Sandor, and Dr. Harris; my surgeon Dr. Leblanc; my pediatricians Dr. Antrim and Dr. Hailey; and Dr. Leora Kuttner, my psychologist who taught me how to prevent and manage my migraines. And a big thanks to CHN for all the support they've given to me and my family.

I'm grateful and proud that I've come through so much and I look forward to what the future holds. My heart condition is just one aspect of my life, and it doesn't hold me back in any way.

Financial (and other) resources for heart families

BY KRISTIN AVIS

It seems almost weekly that a GoFundMe request pops up on my Facebook newsfeed. A child has a sudden, terrible diagnosis and the parents have to take a leave from work to be with their child in the hospital. While the child is fighting for his/her life, the parents have to figure out a way to pay the mortgage and the other bills that life creates. It breaks my heart to read these. I've been there. It's overwhelming and very humbling to have to say to your friends and family that yes, we do need financial help.

Here is a list of resources that have been helpful to my family in our journey.

Service Canada: Care of Critically Ill Child
www.esdc.gc.ca/en/ei/critically_ill_children/index.page
My husband qualified for the Care of Critically Ill Child program from Service Canada. He was able to receive some income (similar to maternity leave) that helped our family significantly during this time. Before the baby was born he qualified for a stress leave, which allowed him to relocate with our family to live near the hospital. We did not find it to be the easiest system to navigate so we suggest you connect with them as early as possible.

BC Family Residency Program
www.BCfamilyresidence.gov.bc.ca
This program provides accommodation for families when their child is receiving medical treatment from Children's Hospital. Up to 30 days per hospital visit. You call them first and then they place your family where there is availability. It could be Easter Seals, Ronald McDonald House, or a hotel close to the hospital.

Variety The Children's Charity
www.variety.bc.ca • 1 866 496-6946
Accommodation subsidy for families. Variety helped our family with accommodation before our baby was born as we did not meet the requirements for the BC Family Residency Program until after the baby was born.

Travel Assistance Program
www2.gov.bc.ca/gov/content/health/accessing-health-care/tap-bc/travel-assistance-program-tap-bc
This form is available from your doctor and will pay travel costs for your child and an escort (for ferry or air) when you need to relocate to Children's Hospital for treatment. We have only used it for the ferry (coming from Vancouver Island) and it covered the vehicle, driver, and patient for a return trip. A huge cost when you're coming from the Island!

Hospital social worker
All of the information I have listed so far would most likely be supplied by the hospital social worker. You may even qualify for more programs. Unfortunately, kids don't always get sick between 9-5 Monday to Friday, and sometimes social workers are off sick too.

Accommodation for families
www.bcchildrens.ca/our-services/your-visit/planning-your-visit
For your support team. BC Children's Hospital offers a list of accommodation near the hospital—many offer medical rates for extended family.

The Children's Heart Network
www.childrensheartnetwork.org
A great resource for before, during, and after your child's treatments, for a $25 yearly membership fee, you are connected to families across the province who have been where you are and love to support other heart families.

Children's Health Foundation of Vancouver Island
https://childrenshealthvi.org/bear-essentials-helps-when-families-need-it-most
A great organization that runs a program called Bear Essentials, among many other initiatives.

Heart moms Kristin Avis and Andrea Van Rossum run the web site The Heart Moms. This article was adapted from the blog "money money monEY!" Visit theheartmoms.com for more posts on the life of a heart mom.

Pearce overcomes obstacles with his huge personality and generous heart

BY DANA KNIGHT

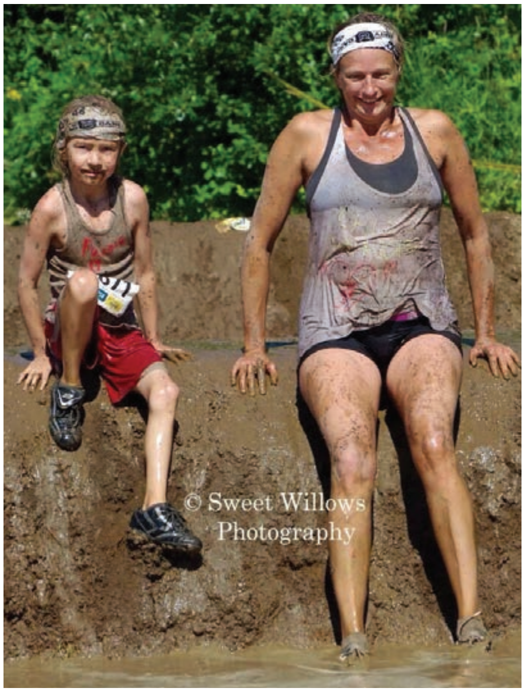
At 6 weeks pregnant I was at work and getting some cramps, which I thought was normal until I felt a gush and knew something was wrong. I went to the hospital in Abbotsford where the ER doctor did an exam said I was still pregnant. I had an internal ultrasound and for the first time I saw and heard Pearce's heartbeat. However, I had lost his twin (I had no idea I was even carrying twins). My heart was broken yet excited that I was still pregnant.

I had Pearce August 18, 2006 in the evening; in the middle of the night a nurse woke me up and said my son had a heart murmur. I wasn't too panicked as my brother had a murmur and he was fine. Dr Cohen then told me his oxygen had dropped to 60% and the flight team was on their way from BC Children's Hospital to get Pearce and a cardiac team was waiting for him. My new-mom bliss quickly turned to gut-wrenching fear. I had to make a tough call to Pearce's dad that our son had something wrong with his heart and he needed to go with him in the helicopter—I couldn't go due to the cesarean.

I had a quick look at Pearce in the incubator with many wires and monitors hooked up to him and then he was gone. Dr Cohen came the next day and tried to explain what was wrong. I didn't get any of it. He had tetralogy of Fallot as well as pulmonary atresia and a VSD. He would have his first surgery the next morning at 36 hours old.

—continued on page 12

Above: Pearce during CHD Awareness Week. Bottom right: Dana and Pearce participating in The Dirty Dash.



PEARCE OVERCOMES OBSTACLES

—continued from page 11

Dr Leblanc did a closed heart surgery under his armpit and placed a BT shunt to allow blood flow to the lungs; he did great! They had also put in an indwelling subcutaneous catheter in his thigh—I would have to give him heparin shots through this twice a day. We went home 12 days after surgery.

After a few days at home Pearce was in pain and started pooping blood, so back to BCCH we went. They determined he was allergic to casein, a protein in cow's milk. I had to go dairy-free in order to breast feed him and we added a hypoallergenic formula to my milk to boost calories.

At 3 months old, Dr Leblanc explained that Pearce was too small and the risk was too high to do the full open heart repair, so he did another BT shunt in the other side of his heart. No more Heparin shots, just half a baby Aspirin a day. The shunt went well and we were home in 5 days.

It was a struggle, but he gradually gained weight and was booked May 17th for his first open heart surgery. Heart-wrenching fear for me; I was numb. It was really hard seeing my little baby in ICU for the third time in just his first 9 months of life. Dr Leblanc gave Pearce a bovine artery and closed his large VSD. Pearce had some ups and downs in ICU but he overcame them and 5 days later we were home!

I didn't know about the Children's Heart Network at the time. Now I do and I have had so much support and made amazing friends through CHN! I attend coffee groups and we love the events (aquarium, Christmas party, bowling, water slides, pumpkin patch, and more.)

Pearce did well until February 2012 when his ECG showed he only had 60% pressure so he was booked in for a heart catheterization in April. During the cath they cleared some scar tissue to buy him a few more years before his next surgery. That spring was tough; we lost Pearce's dad and it was a huge shock.

When Pearce was in kindergarten I learned he has ADHD, a sensory processing disorder, learning challenges, anxiety and PTSD. He is a lot of work and sometimes I get judged by other parents for his behavior. It is not easy being a single mom but he is such a sweet little boy who has endured so much in his little life, I wouldn't trade it for the world!

One night last spring Pearce's heart rate was rapid and his breathing was weak, so I took him to Abbotsford ER. They ran tests that all came back fine, but the next day the hospital called and told me to bring him back right away as some of the blood cultures they took were already growing bacteria. They gave him an IV and admitted us. He had group B streptococcus, possibly endocarditis. We spent 2 nights in Abbotsford then we were transferred via ambulance to BCCH, where they confirmed the endocarditis. We spent 10 days at BCCH, where Pearce went through 5 IVs due to playing too much air hockey and foosball. He was always in trouble for riding down the hallways with his IV!

We went home with a PICC line (IV catheter), which meant no swimming or getting it wet—and it was the hottest summer ever! He recovered, had the PICC line removed, and we had 18 days of summer before his next open heart surgery, booked for August 17, 2015, the day before his 9th birthday. We had lots of pool time and a camping trip where we visited a young girl named Maya whom he befriended at BCCH. We made the most of those three weeks!

The night before the surgery we headed to Easter Seals House and Pearce, for the first time, got scared. I pulled over in Aldergrove and put out a Facebook request to please send positive notes to support Pearce. As I continued to drive my mom read each post, they made him feel like he could conquer the world!

The surgery went well. In ICU he was sleepy but awake, and gave the thumbs up, Pearce style. The following day, his 9th birthday, he was moved up to the cardiac ward and a few days later we were home. He is doing fabulously.

Having a child with CHD is very scary; I check his breathing every night. When the school calls I immediately ask "is he ok?" This is our life and we do our best. Pearce is a very active, outgoing boy with a huge personality, beautiful soul, and an amazing, giving heart! He is growing his hair to donate for cancer and gets teased about it sometimes, but he is proud to be helping other kids.

Parking at BC Children's? Use the free valet

If you're having trouble finding parking at BC Children's Hospital you can have your car valet parked. They will charge you the same price that you would pay for your parking! Thus, no charge to have your car parked for you. Just pull up outside the ER and look for the Free Valet Parking sign.